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ABSTRACT

This theme issue focuses on early intervention. The four articles presented on this theme are: (1) "Deaf Infants, Hearing Mothers: A Research Report" (Kathryn P. Meadow-Orlans, and others), reporting findings on effects of auditory loss on early development; (2) "Maintaining Involvement of Inner City Families in Early Intervention Programs through a Program of Incentives: Looking beyond Family Systems to Societal Systems" (Richard P. Brinket, and others) stressing the need for an integrated approach to family services; (3) "Interdisciplinary Interagency Training for Professionals Serving Chemically Dependent Families" (Vicki Krodenski, and others), describing a California program providing interdisciplinary and interagency training to work with this population; (4) "Policy Implementation of Services for Infants and Toddlers with Developmental Delays" (James Gallagher, and others), describing a project to track implementation of Part H of the Individuals with Disabilities Education Act. A special subsection on attention deficit disorders include the following articles: "A Clarification of State and Local Responsibility under Federal Law To Address the Needs of Children with Attention Deficit Disorders" (a Department of Education policy memorandum); "OSEP's Initiatives for Meeting the Needs of Children with Attention Deficit Disorders" (Ellen Schiller and Jane Hauser); and "Attention Deficit Disorders: Academic Functioning and Stimulant Medication" (Steven R. Forness). (DB)

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Winter 1992

Volume IV, Number 3

Early Intervention

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UNITED STATES DEPARTMENT OF EDUCATION

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A Message from the Assistant Secretary

Robert R. Davila, Ph.D

Part H of the Individuals with Disabilities Education Act (IDEA), originally passed in 1986, states that the Congress found an urgent and substantial need to:

(1) enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay;

(2) reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;

(3) minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential for their independent living in society; and

(4) enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.

In creating the Infants and Toddlers with Disabilities Program, the Congress provided families with a vision and a promise of a coordinated system of services to help ensure the growth and development of their young children with disabilities. This program was special in its design because it focused on the family's role of nurturing young children with disabilities. The legislation sought to support that role by drawing together an often fragmented system of services to meet the unique needs of infants and toddlers with disabilities, through an emphasis on interagency cooperation and service coordination. At the same time, Congress authorized grants for preschool services for children ages three through five, for the purpose of ensuring provision of a free appropriate public education to each eligible child with disabilities.

Since 1975, the nation's special education laws have steadily expanded the variety and availability of services for children and youth with disabilities from birth through age 21. Preschool programs are now or soon will be available for every child with a disability. Each state is in the process of implementing early intervention services for infants and toddlers with disabilities and their families. State and local school authorities and others have been extremely responsive and resourceful in working toward ensuring the availability of high quality services for young children with disabilities and their families.

These programs are founded on the principle that every child has potential, including children with disabilities. Research has shown that early intervention and preschool programs can make a difference for children with disabilities by easing the transition from home to elementary school and maximizing their opportunities for interaction with their nondisabled peers. These programs empower parents, too, by providing the information and services they need to attend to their child's unique needs.

Early intervention programs have an important role in helping meet the first of our nation's education goals, adopted by President Bush and the governors in 1990: by the year 2000, all children in America will start school ready to learn. In support of this national effort, I have identified the support of early intervention services as a key area for OSERS during the next few years. Very simply, this means that OSERS will support activities that encourage the earliest and most effective provision of services for infants and young children with disabilities to ensure that all children enter school ready to learn.

As part of our early intervention efforts, we will work with states to ensure their continued participation in Part H and preschool programs. Federal funding priorities related to this initiative will continue to provide technical assistance to early intervention projects, develop creative and effective learning plans and curricula for young children, and support early detection programs. Priorities that support training for family members, teachers, and other early childhood professionals will help ensure that infants and toddlers with disabilities will receive services from well-trained providers.

The real benefit of effective education and rehabilitation, including early intervention programs, is in the opportunity for children and adults with disabilities to achieve their full potential. Expectations for outcomes for people with disabilities are higher than ever before, and I hope they will become even higher. I have often spoken of OSERS' mission of providing opportunities for people with disabilities to achieve their individual potential and maximum participation and productivity in society. Early intervention will help make this goal a reality.

Early Intervention

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DEAF INFANTS, HEARING MOTHERS: A Research Report

Kathryn P. Meadow-Orlans, Ph.D.

Robert H. MacTurk, Ph.D.

Patricia E. Spencer, Ph.D.

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Introduction

In the past decade, there has been an enormous expansion in knowledge about infants' development in the first year of life, particularly in relation to their capacities to regulate social and emotional interaction, to respond to objects and to their parents, and to influence their environment by these responses. Knowledge about the process of language acquisition also has grown exponentially.

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Infants who are deaf, however, have been studied very little, and available research reports include only a few subjects. A major reason for this gap is a continuing delay in the detection of congenital deafness. Despite advances in diagnostic procedures and practices, hearing loss is generally not identified before the age of eighteen months. As early intervention specialists address the requirements for providing services to children from birth to age three, as mandated in the Education For All Handicapped Children Act, P.L. 99-457, the absence of developmental research on infants who are deaf creates serious problems.

In response to this situation, the research summarized here' was designed to investigate the impact of hearing loss on early mother-infant interaction, on infants' motivation to learn about objects, their social coping skills, and their early language. These developmental domains were viewed in the context of the family stress created by the diagnosis of deafness and the network of social support available to parents. The purposes of the study were to provide information to behavioral scientists about the influence of auditory loss on early development, and to provide a basis for informed intervention to parents and educators.

Study Design and Methods:

Twenty normally-developing infants with hearing loss were recruited from five metropolitan areas; infants with normal hearing were matched with that group for sex and mother's education. Infants' hearing losses were diagnosed by the age of seven months; fifteen had a hearing loss in the severe to profound range, five had a less severe loss. Families were primarily intact, white, middle-class, and college-educated.

Data were collected when infants were 9-, 12-, 15-, and 18-months of age. The 15-month contact was a home visit during which the mother was interviewed. Other contacts were in a laboratory at one of the five research sites. (In addition to Gallaudet University, participating research groups were based at the University of Texas at Dallas; the University of Pittsburgh; the University of Massachusetts, and Amherst/Boston; Georgia State University, Atlanta.)

At the *9-month* visit, mothers and infants were videotaped in a standard Face-to-Face interaction format, with two three-minute intervals of normal interaction separated by a Still-Face episode where mothers were instructed to be non-responsive. Mastery Motivation was assessed by the presentation of four age-appropriate toys. An interview was conducted and questionnaire data on family stress and support were collected.

During the *12-month* visit, Mastery Motivation was assessed a second time; mothers and children participated in a fifteen-minute unstructured play session, and in the "Strange Situation," a standard laboratory procedure for assessing infants' attachment to their mothers through a series of brief separations and reunions.

At *eighteen months*, mothers and children were again engaged in the Strange Situation and in twenty minutes of free play. Another interview was conducted and additional questionnaire data collected.

Findings:

On several measures, families with infants who were deaf or had hearing loss reported significantly higher levels of stress *and* higher levels of social support. Differences in stress levels were accounted for primarily by stress related to care of the newborn child; differences in support levels were accounted for by services provided by intervention specialists.

Infant Mastery Motivation. Deaf and hearing infants did not differ in their persistence in efforts to master objects, either at nine or at twelve months of age. *However*, social gaze behaviors directed to the examiner or to the mother at nine months predicted mastery motivation (persistence) at twelve months for the deaf (but not the hearing) infants.

Infant Social Coping Skills. At age nine months, hearing infants were more likely to elicit responses from their mothers during the Still-Face situation, while deaf infants were more likely to exhibit self-comforting behaviors. This was interpreted as reflecting a tendency to internalize their discomfort, compared to the hearing infants' more active efforts to repair the disrupted interaction.

At eighteen months there were no differences in the deaf and hearing infants' quality of attachment to their mothers. On the basis of more specific sub-categories of behavior, infants who were deaf responded to separation by exhibiting greater *avoidance* at the reunions, compared to the hearing infants.

Infant Communicative Abilities. Hearing infants and infants who were deaf did not differ in their production of prelinguistic visual-gestural communication, in the quantity of vocal communication, or in frequency of intentional communication either at twelve or at eighteen months. Hearing infants' vocal productions were more sophisticated and their use of formal language was more advanced, compared to the infants who were deaf. However, there was great variation within the two groups. The language performance of some individual infants who were deaf exceeded that of some individual hearing infants.

Mother-Infant Interactions. At nine, twelve, and eighteen months, mothers with infants who were deaf exhibited a positive adaptation to

infants' auditory deprivation by providing more visual cues than did mothers with hearing infants. However, at nine months, mothers with hearing infants were judged to be more *responsive* to their babies (in the Face-to-Face format), and at eighteen months, mothers with hearing infants were judged to be more *sensitive* to their babies (in the free play setting) compared to mothers with deaf infants. Spoken language of mothers with hearing infants was more *contingent* on infants' visual attention at twelve and eighteen months, compared to the spoken language of mothers with infants who were deaf.

Development of Social Interaction and Language from Nine to Eighteen Months of Age. Based on results of previous research, we had predicted that the groups of hearing mothers with deaf and with hearing infants would display varying patterns of interaction and mastery motivation at ages nine and twelve months, and that these patterns would predict differences in the quality of mother-infant interaction and in infants' language levels at eighteen months. We also predicted that these patterns of interaction and language development would be specified by family stress and social support.

Quality of Mother-Infant Interaction. Based on qualitative ratings of mothers and infants at eighteen months, a global score was assigned to reflect the overall quality of dyadic interaction. Four predictor variables were identified: family Social Support; infant Social Smile during Mastery assessment at nine months; infant Gaze Avert during the Still-Face episode of Face-to-Face interaction at nine months; dyadic Responsiveness during normal Face-to-Face interaction at nine months). These four variables accounted for slightly less than one-third of the findings (that is, the variance) in interactions of dyads with hearing infants, but most (79 percent) of the variance in interactions of dyads with deaf infants at eighteen months. Of special note is the strong positive impact of family social support on the quality of interactions in mothers and deaf infants.

Infants' Language Level. The second outcome measure was an infant Language Level Index from the eighteen-month communication data. Two predictor variables were identified for this measure: mother-infant Affective Match and mothers' visual-tactile Responsiveness (both from Face-to-Face data at nine months). These variables accounted for 37 percent of the variance in language level for the hearing infants, but none of the variance in the deaf infants' language levels.

Recommendations

Recommendation 1. Increased support for early identification, of and intervention with, deaf infants, including the establishment of statewide Child Find systems or registries and early hearing screening programs.

The single most important recommendation we can make is the broadening of programs for early identification and intervention with infants who are deaf. Although the technology exists for diagnosis even before the age of nine months, two and one-half years of strenuous effort in five major metropolitan areas were required to recruit the twenty infants who were deaf that were targeted for this project. Child-Find activities apparently are not as advanced as most professionals would like to believe. Particularly evident is the absence of infants from poor, disadvantaged, minority group, or single-parent families in our research group. We deduce that families without the advantages of access to appropriate health care are likely to experience even greater delays in diagnosis than the advantaged, white, middle class families. Thus, a key recommendation is that state-wide efforts be made to establish at-risk registries and hearing screening programs.

Legislation to support this is in place (P.L. 99-457), and many states have begun their work in this direction. This cannot be done too soon if infants who are deaf are to receive the clear benefits that come from an early diagnosis.

Recommendation 2. Pediatricians and other health professionals should be alert for early suggestions of impaired hearing and should refer infants for thorough auditory assessments as soon as hearing loss is suspected.

Our findings suggest that early diagnosis is even more important for infants who are deaf than previous work had indicated. Health professionals likely to have early contact with infants and their families must know that hearing can be tested reliably during the first weeks of life. Referrals to early intervention programs immediately after diagnosis is critical.

Recommendation 3. Training programs for health professionals should expand their emphasis on skills in interacting with and counseling parents of infants with disabilities.

One of the most significant findings from this research is the strong rela-

tionship between social support received by mothers of infants who are deaf and the quality of their interactions with those infants. The source of support differentiating mothers with infants who are deaf from mothers with hearing infants was that provided by professionals. We interpret this set of results as a clear reflection of the importance of professionals' support for families in the early stages of their adaptation to the diagnosis of deafness, and as a clear mandate to early intervention specialists to continue and to expand their provision of emotional support/counseling to families of infants who are deaf.

Recommendation 4.
Parents should receive realistic, clear information about their infant's ability to perceive language in the auditory mode, and be informed about implications for choice of communication mode.

Our research showed that infants with severe to profound hearing losses could acquire expressive language at a normal rate when they were provided language in a modality they could perceive. In order to make informed decisions about language methods, parents need to have: (a) information from intensive auditory assessments, made on a regular basis and providing measures of infants' ability to perceive sound with and without amplification; (b) information from assessments of progress in communication/language development on a regular basis; and, (c) information about language methods available to parents.

Recommendation 5.
Additional research is needed with other populations, especially infants who are deaf with parents who are deaf and deaf infants from disadvantaged families. Research focused specifically on deaf infants' processing of visual information and signaling strategies during social interaction is also recommended.**

Conclusion

This research provides a rich database and intriguing new information about the importance of family stress and support for the development of infants with deafness and their early interactions with mothers. Additional research is needed, however, to provide information enabling infants with deafness and their parents to accommodate successfully to the infants' auditory loss.

* This research was supported by the Division of Maternal and Child Health, Bureau of Health Care Delivery and Assistance (Grant #MCJ-110563) and by the Gallaudet Research Institute. Copies of the Final Report ("Interaction and Support: Mothers and Deaf Infants") may be obtained for a fee from the National Technical Information Service, U.S. Department of Commerce, Springfield, VA 22161

** This research group has been awarded a grant (H023C10077) from the Office of Special Education and Rehabilitative Services for analysis of comparable data from deaf and hearing infants with deaf parents: "Maternal Responsiveness and Child Competency in Deaf and Hearing Children," Donald F. Moores, Principal Investigator, Kathryn P. Meadow-Orlans, Co-Principal Investigator, Robert H. MacTurk, Patricia E. Spencer, Lynne Sanford Koester, Research Scientists.

Maintaining Involvement of Inner City Families in Early Intervention Programs Through a Program of Incentives:

Looking Beyond Family Systems to Societal Systems

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Introduction

The problem with the partnership between families and early intervention programs envisaged in the Education of the Handicapped Act Amendments of 1986 is that it presumes some congruence in beliefs of professionals and parents. Families living in poverty in the inner cities of America may not have many similarities with professionals and paraprofessionals employed in early intervention programs. Hence, the belief that professionals wish to work as partners with a family from the inner city whose child is developmentally disabled may not be held by such families. Neither may the perception of the child's disability be shared by early intervention professionals and inner city families with an infant who is disabled. The problem that we have faced in providing early intervention to infants with disabilities and their families who live in poverty is that significant life stresses place the child's developmental needs (and hence the need for the early intervention program) at a lower priority than we have experienced to be the case when families come from middle and higher socioeconomic backgrounds.

The purpose of this paper is to review efforts to increase the involvement of inner city families in early intervention through the expansion of intervention services to include services to families in an effort to reduce barriers to their involvement in inter-

vention services for their children. First, we will briefly review the need to expand the perspective of intervention beyond the developmental needs of the child with disabilities. Then we will briefly review a project designed to provide individualized incentives to overcome barriers to participation in early intervention and present some preliminary data from this effort. Finally, we will describe the need for a systems perspective and illustrate this need with brief descriptions of some of the families involved in the experimental incentives program.

Reluctance to Become Involved in Early Intervention

The Early Childhood Research and Intervention Program (ECRIP) of the Institute for Study of Developmental Disabilities at University of Illinois at Chicago has been in existence for over twenty years. Although the program is located in the inner city, until a few years ago most of the clients were middle class, non-minority families commuting from the suburbs. It was clear from involvement with hospital follow-up programs that, although many inner city families were being referred to ECRIP, not many were successfully enrolling their infants with disabilities and participating in the weekly program. Several studies conducted by ECRIP confirmed the problem of identifying and serving infants with disabilities from the inner city.

In a pilot study of developmental screening in two Chicago Board of Health clinics, (Brinker, Frazier, Lancelot, & Norman, 1989) our staff screened 579 infants between the ages of four and twenty-four months for developmental delays using the Infant Monitoring System, a parent-questionnaire developed by Bricker (1984). Of the infants screened, 115 (20 percent) were identified as suspect for delayed development. After screening, 20 percent of the suspect cases could not be located by the clinics or case managers for further consideration of the child's developmental status. Seventy-six cases were referred to case managers for further study. Of these, only eleven families remained in contact with case managers and agreed to multidisciplinary evaluations. Thus, only 10 percent of the population identified as suspect agreed to any further evaluation. Of those infants whose families agreed to evaluation only five were actually evaluated. Only 4 percent of the infants identified as suspect or delayed developmentally were actually evaluated to confirm or disconfirm the problem.

The screening effort illustrates two aspects of the mechanism by which low income families become disenfranchised from available services. First, many of the families demonstrated that obtaining a full developmental assessment was a low priority

when the screening (which was completed by the family) indicated the baby's development was suspect (Bricker, Squires, Kaminsky & Mount, 1988). Second, this prioritizing may be an adaptive response learned from previous encounters with a system of health care, education, and social services that a) is slow to meet individuals' needs and b) offers a fixed institutionalized pattern of service that is not tailored to individuals. The fact that case managers were able to maintain active contact with only eleven of seventy-six families reflects such systemic problems.

Four other ECRIP projects have demonstrated inconsistencies in program attendance by very low income families. In addition to the participation in developmental screening, these projects have monitored participation in neonatal developmental follow-up clinics; intake and enrollment following referral for early intervention; attendance during a weekly early intervention program; and attendance in a monthly toy lending project to provide family support and play consultations. Data regarding participation and drop out is provided in Table 1. In addition, our contacts with other Early Intervention Programs in the Chicago Consortium of Early Intervention Service Providers suggest that inconsistent attendance results in as much as 30 to 50 percent of missed contacts, across home-based, center-based, individual and group treatment models. The pattern of inconsistent utilization of intervention services by poor families with young children with disabilities appears to be pervasive throughout the service delivery system in Chicago.

The available research literature on inner city families with infants who have disabilities does confirm our experience regarding participation in early intervention services. Children's development often is not viewed as something over which the family living in poverty has much control (Bickerstaff, 1980). The family may neither be aware of their impact upon their children's development nor have considered the possibility that current parental efforts and intervention efforts can alleviate subsequent problems (Badger, 1985; Bickerstaff, 1980; Bromwich, 1981; Ogbu, 1987). The incentives framework is based upon the perspective that the failure of economically disadvantaged families to utilize professionally recommended services is more than a compliance issue. Lack of involvement in early intervention may be attributed to the circumstances of family life. Dunst (1987) has conceptualized a hierarchical framework of specific major categories of needs. Individuals in need are most likely to place emphasis on meeting needs that are at the top of the hierarchy (Lewin, 1931; Hull, 1943; Murray, 1938; and Maslow, 1954). The most basic survival needs "dominate" behavior and when unmet, prevent satisfaction of higher-level needs being addressed (Dunst, 1987).

Summary of Attendance And Follow-Through on Recommendations Concerning Child Developmental Services

Infants discharged from NICU who attend neonatal developmental clinics in the first year	25%
Referrals to Early Intervention who fail to appear at intake after repeated rescheduling	23%
Weekly Intervention sessions attended prior to dropout	33%
Monthly toy library sessions attended by very low income families who drop out within the first six months	54%

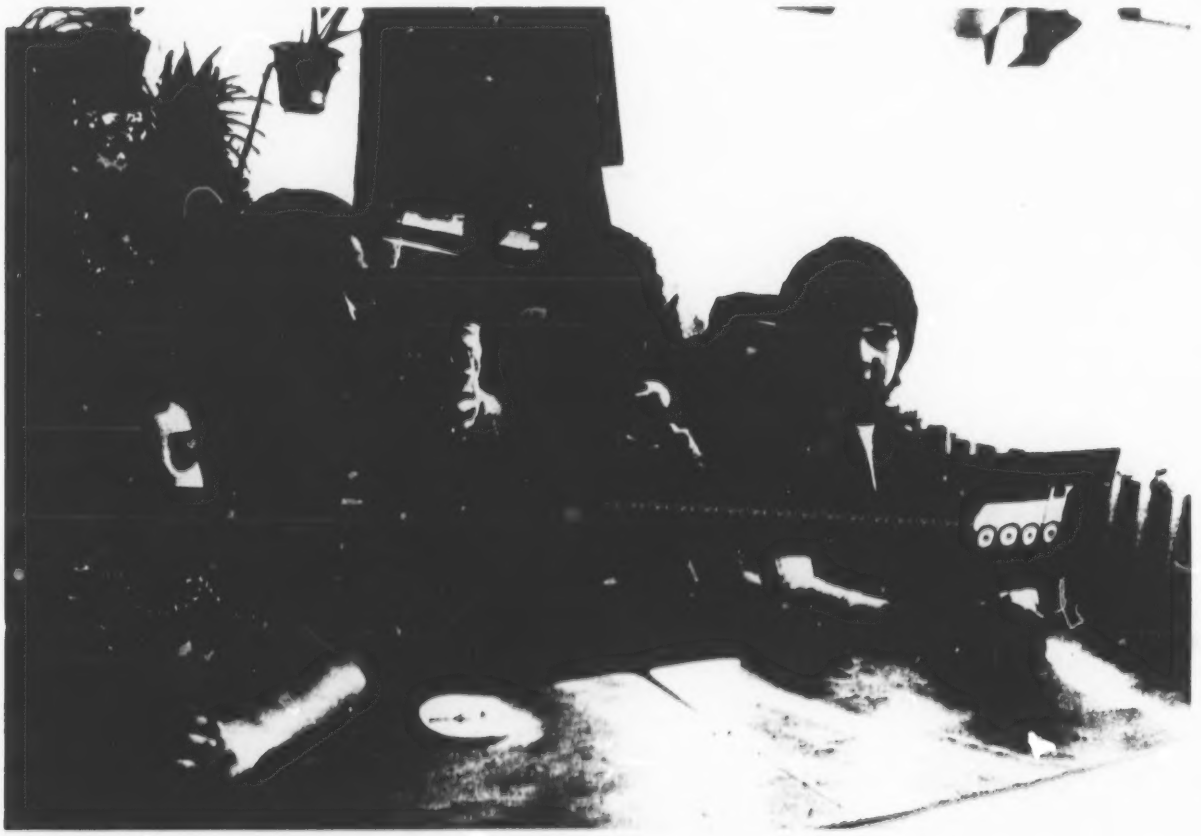
In attempting to understand how needs influence behavior, Garbarino (1982) adapted the notion of "environmental press." He suggests that a set of conditions in an environment shape the behavior of individuals within the environment and guide individuals in a particular direction. The most important needs at a particular point in time will most likely become priorities. The construct of environmental press has implications for working with families in an inner city environment. The interactions between family resources, economic pressures, and priorities indicate that efforts need to be made to meet basic family needs in order for families to have the energy and personal investment to maintain involvement with services on behalf of their child who is developmentally disabled. Unfortunately, this is typically not done by early intervention programs. Most programs offer information to families without determining the family's priority for such information.

In order to improve the level of involvement of inner city families in early intervention programs, we offered tangible incentives to a ran-

domly selected group of inner city families that had been referred to ECRIP. The incentives were individually identified by families as needed to reduce barriers to seeking and utilizing existing community intervention services. Barriers were the result of economic pressures, an inability to access existing resources, and personal priorities that influence family responsiveness and commitment to intervention efforts for their child with a developmental disability. A fundamentally important component was that the families participating in the project identified individual needs and priorities and selected incentives to motivate them to enroll in early intervention services.

Thus, the scope of our involvement as interventionists was broadened for the experimental incentive group to include their most pressing life needs rather than only those needs revolving around services to the child with disabilities. In this study, we proposed a hierarchy of different types of incentives related to the hierarchy of needs or level of environmental press. Specific tangible commodities such as food, shelter, and clothing were thought to constitute the most motivating types of incentives for families struggling with basic survival needs. Once basic survival needs were met, a number of other tangible incentives related to the quality of life might emerge as highly reinforcing. The quality of specific human relationships has perhaps the strongest incentive value once threats to physical survival are reduced. Finally, information about one's self, one's children, and the surrounding environment may acquire incentive value once it is recognized how such knowledge can enrich one's relationships.

Other efforts to involve low income parents to take advantage of available community resources and to take an active role in their children's development is a question that has been addressed only cursorily by the research literature (Finney, Lemanek, Brophy, & Cataldo, 1990; LaGreca, 1990; Saylor, Elksnin, Farah, & Pope, 1990). Three issues emerge from reviewing studies using incentives to motivate economically disadvantaged families to alter some aspect of their behavior. In all of the studies reviewed, incentives were predetermined by the researcher. Fisher (1983) suggests that help is maximally effective when aid and assistance are con-



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gruent with the help seeker's appraisal of his or her problems or needs. Secondly, in none of the studies were incentives individualized. While it is generally possible to specify major categories of incentives with high probability of motivation to an economically disadvantaged population, motivation is a relative phenomenon. It cannot be assumed that a reward to one family is rewarding to another. Finally, in previous studies incentive systems were conceptualized from the standpoint of a noncompliance issue. Life circumstances were not considered in detail in the experimental designs. Incentives were not offered as potentially reducing or eliminating specific reasons for noncompliance.

Criteria for enrollment. Once referral to ECRIP had been made, families were selected for inclusion in the current project based on the following criteria: 1) family demonstration of a lack of involvement in early intervention services or inability to sustain attendance over time, and 2) the presence of demographic risk factors. Previous experience had suggested that failure to attend intake appointments without proper notification is highly prognostic of future attendance in the program. Thus, any family who failed to attend or who repeatedly canceled intake appointments for unspecified reasons met the initial criterion for inclusion. Attendance failure at an intake appointment without an attempt to cancel or reschedule the appointment was deemed sufficient for meeting this criterion. Repeated cancellations were defined as two cancellations within three consecutive appointments. Many families comply with intake procedures yet discontinued participation in the early stages of the program. For this reason, families who attended less than four of the first eight sessions were also eligible for random assignment to the incentive or comparison conditions of the project.

Our assumption that certain environmental factors can place families at risk for under-utilization of early intervention resources led us to an additional criterion. The mere presence of demographic characteristics such as single and/or teenage parenthood, ethnic minority status, and large family size, in addition to the birth of a child with developmental disabilities, has been demonstrated to intensify the need for early intervention services (Eheart & Ciccone, 1982). Thus, subject families had to exhibit one or more of these characteristics. Finally, all children met the usual program entrance requirements.

Group Assignment. Families with infants who meet the criteria for inclusion (i.e., missed appointments, or successively canceled appointments or poor attendance) were randomly

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assigned to either the experimental or comparison conditions. The experimental group met individually with an incentive counselor at each session attended to select an incentive that might reduce a barrier for participation in the program. The comparison group was offered the same program but was not systematically provided with incentives. This comparison condition was assignment to the regular ECRIP program which included case management that essentially provided the clients with referral information for any family resources that extended beyond the identified needs of the infant with disabilities. Thus, the comparison group was more specifically focused on issues of the child's disabilities without direct provision (other than referral) of resources focused on the whole family. The one exception to differentiation of the incentive from the comparison group was that both groups received Christmas baskets of toys, food, and other household commodities at that holiday.

Impact of Incentives on Participating Families and ECRIP

The program of incentives created a new consciousness among ECRIP staff that led collectively to improvements in enrolling low income families referred to the program. In the first year of the program, the number of families attending an intake appointment at ECRIP after referral increased from 69 percent to 87 percent of the families referred. More importantly the number of families with extremely limited financial resources (less than $15,000 per year) who were referred, completed intake, and began participation in the program increased from 25 percent of the families six months prior to the incentives project to 76 percent in the first six months of the project. These effects for the first two years of the incentives program are depicted in Figure 1. The net effect has been a statistically sig-

Figure 1: Summary of Referrals and Group Assignment

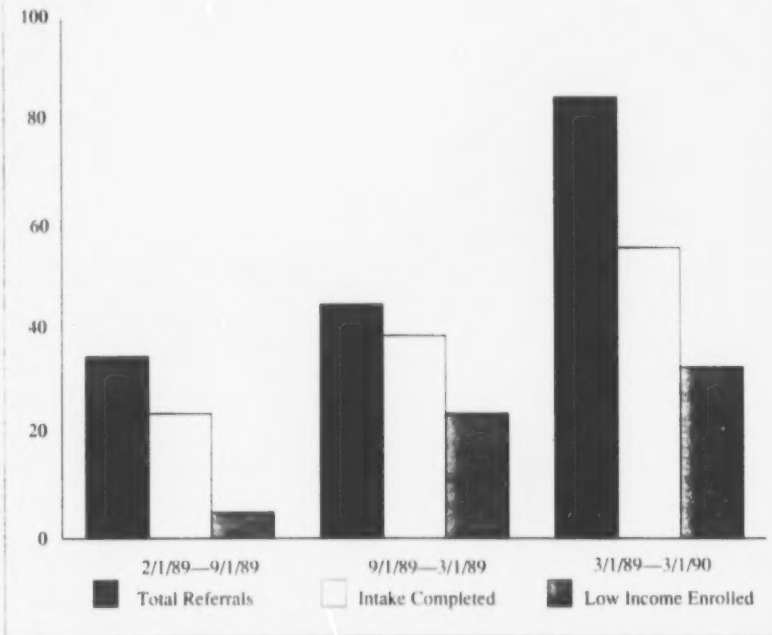
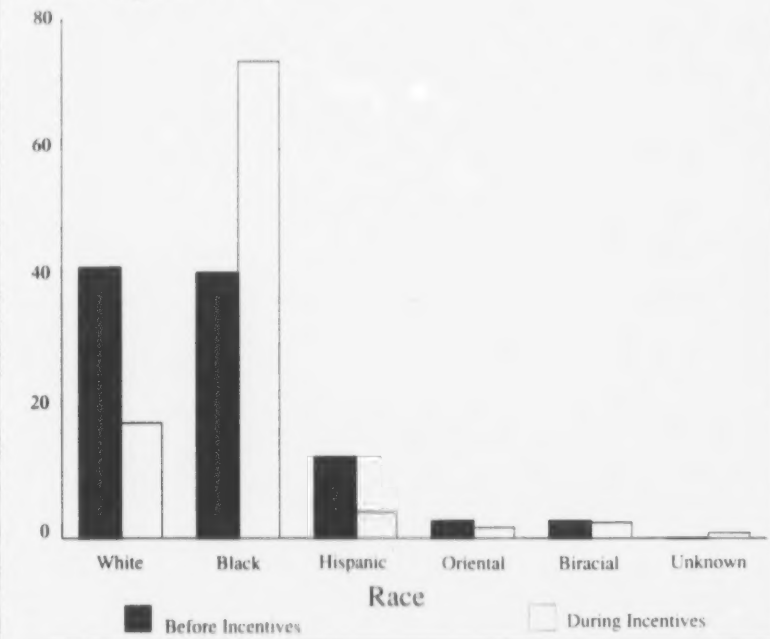


Figure 2: Race of ECRIP Families Before and During Incentives Program



nificant shift in the socioeconomic status (using Hollingshead's two factor weighted score that includes head of household, occupation, and maternal education) such that the ECRIP population of about seventy families represents a significantly less affluent population than prior to the onset of the incentives program. The specific changes in the demographics of families served by ECRIP presently, in comparison to the time prior to the incentives program, are depicted for the variables race, marital status, and maternal education in Figures 2 through 4, respectively. The chi-square values for race and marital status are statistically significant ($p < .001$ for race and marital status; $p < .05$ for maternal education). In addition, the largest single etiological group is now those infants exposed to illegal drugs prenatally, a group that comprised very little of the ECRIP population prior to the incentives program.

The shift in program population caused a change in program characteristics that cannot be directly attributed to the incentives counseling per se. Unfortunately, for those families referred to the experimental treatment in which personal life barriers were discussed and incentives selected in individual counseling sessions, attendance at ECRIP is no better than for families assigned to the comparison group with no incentives. Approximately 40 percent to 45 percent of the sessions have been attended by those families receiving incentives counseling. Overall attendance by all ECRIP families has been reduced since the onset of the incentives program.

Discussion of specific cases that unfortunately are not atypical may clarify why provision of weekly incentives did not significantly enhance program participation relative to families not receiving incentives.

Figure 3: Marital Status of ECRIP Families Before and During Incentives Program

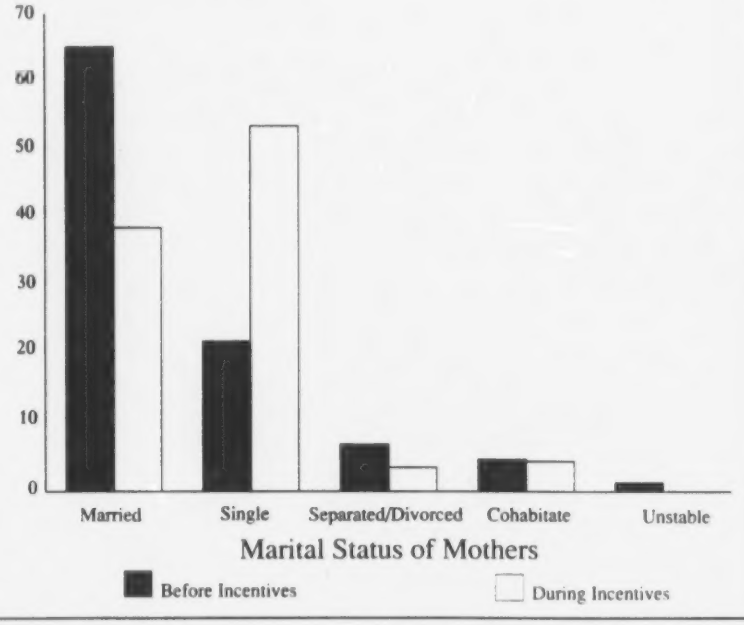
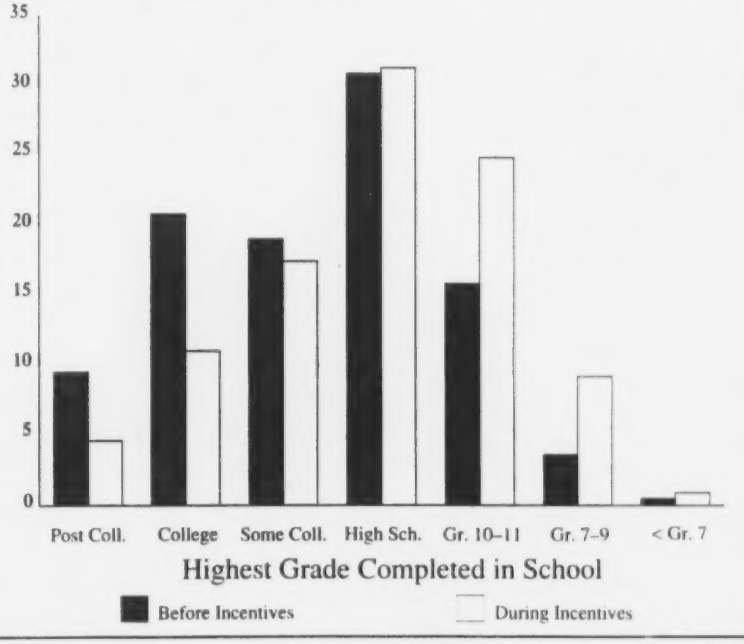


Figure 4: ECRIP Mothers' Educational Attainment Before and During Incentives Program



Debbie J. was an 11-month-old girl referred to ECRIP because of suspected developmental delay and prenatal exposure to cocaine. Debbie attended the program accompanied by her father, Larry, who had given up his employment to care for Debbie and her 5-year-old sister. The mother of the children was enrolled in an inpatient drug addictions treatment program by court order. The Department of Children and Family Services (DCFS) care plan restricted the mother from providing care of her children until addictions treatment was completed and the situation was re-evaluated. Larry J. was involved i the incentive program and attended regularly. Initially his interactions with his daughter occurred at a very rapid pace, with many toys being presented to her regardless of her response or the focus of her attention. In the parent support group, Mr. J. requested input on cooking and housekeeping. After approximately eight months of involvement with ECRIP, Mr. J. said he now realized the importance of his behavior as it influenced his daughter's development. At this point he became quite emotional and indicated that he had been a heroin addict and was again using heroin since his wife had moved back home. He requested assistance in finding a temporary foster care arrangement until he and his wife could better care for Debbie and her sister. The ECRIP social worker then called the DCFS caseworker to explore possible short-term respite care arrangements. The DCFS case worker recommended to the ECRIP social worker that because the family was in violation of the court order, since the child's mother was now living at home, a report would need to be filed with the Child Abuse Hot Line. That was done and an investigator found the children in the care of a babysitter and reported no immediate emergency that would justify further action. At that point Larry and his family went underground, indicating that he no longer trusted the ECRIP program that had tried to take his children from him by reporting him to the Child Abuse Hot Line. The mother and Debbie came to the program on two occasions after Larry dropped out, but have refused involvement in early intervention.

The above case illustrates problems that unfortunately have been common across many of the families involved in the incentives program. The first recurrent feature is that there seems to be a risk to continued involvement with families that is related to increased realization by the parents of their role in the development of their infants. Thus, when Larry first expressed his understanding of his own and his wife's influence on Debbie's development, this understanding was

accompanied by panic over his drug dependence. The outcome was that the family rejected any further support and their daughter with disabilities received no further intervention.

This scenario was repeated with another mother, dependent upon drugs, who maintained close involvement with the program in spite of the fact that she lived on the streets or in shelters with her children. However, her stress increased when she was successful in obtaining a housing lease in one of the Chicago Urban League's transitional homes. After this mother moved in with her children and her few belongings, contained in shopping bags, her desperation seemed to increase as did her drug use. After three weeks the fact of safe housing that kept her family off the streets paled in the face of the reality that she had no furniture, no cooking utensils, and no money. At that point she requested assistance from DCFS but these materials were not provided. Rather the DCFS response was to disperse the children, including the baby with developmental disabilities, into a variety of foster care arrangements. The foster parents were not able to continue involvement in early intervention for the baby.

The second feature common in both cases was that the child welfare agency involved in these cases seemed to have only one response: taking custody of the children. In Larry's case, even though the family had a DCFS caseworker, that individual did not investigate the family situation personally or trust our social worker, who recommended respite care through DCFS support. Rather the case was assigned to an impersonal child abuse prevention process administered by the same agency. In the second case, assistance in the form of basic home furnishings was not a possibility from the child welfare system in spite of this mother's commitment to early intervention for one of her children during the preceding several months.

Conclusions

To the families who have infants with disabilities, and who live in extremely desperate circumstances, it may have seemed that our efforts were often like trying to light a fire in a hurricane. With our focused research design and outcome measures, it is easier to document the heap of burnt matches than the light or warmth of the fire we intended.

However, five families who said they didn't attend early intervention because they were afraid to leave their high rise apartments in public housing projects that were controlled by gangs did get apartments in less dangerous neighborhoods through our incentives program. One mother obtained employment in a bank as part of her incentives program. Many weeks food provided by the program was used to prepare meals that might not otherwise have been had. Babies had clean diapers more often than they might have had because they selected disposable diapers as their incentive. Families learned that they qualified for services for crippled children and obtained a variety of adaptive equipment through that resource.

Nevertheless, our goals of improved attendance and a shift from tangible incentives to personal relationships and information about intervention techniques as incentives was not achieved. The project did confirm our initial perceptions that, for chronically disadvantaged families, the focus of involvement needs to be extended beyond the dyad of the family member and the child with disabilities to include the interface with the entire family system. Yet in confronting the environmental press upon the family, it has become clear that a larger ecological perspective is required (Hobbs, Dokecki, Hoover-Dempsey, Moroney, Shayne, & Weeks, 1984). That perspective needs to include a systemic focus not only on the families but also on the myriad of agencies and resources designed to support the family. Because the helping system of agencies has been conceptualized narrowly around specific aspects of environmental press, for example housing or food subsidies or child welfare, no collation of resources seems sufficiently integrated to effectively address the child's and family's problems.

The implication of our research is that systems thinking must expand beyond the family-child system to the community and societal systems. Many of the child welfare workers with whom we are in contact are disempowered in terms of their own ability to access resources which they know would more effectively address the needs of a family. There needs to be a system for heralding their efforts at creative problem solving in collaboration with other agencies. Unfortunately, because services to families are not conceptualized as an integrated whole, there are negative sanctions upon case workers who overstep the boundaries of an agency's specific statutory responsibilities. Thus, the adoption of systems analysis of family needs requires a coordinated adoption of family support strategies across agencies (Schorr, 1988). While P.L. 99-457 provides a framework for such a coordinated interagency approach, the historical functioning of bureaucracies provides considerable inertia that acts against such change. While the incentives effort at ECRIP provided greater access to early intervention services for low income families

than had occurred previously, our hopes regarding increased utilization of these services and effective bridges across agencies to access and coordinate resources were not satisfied.

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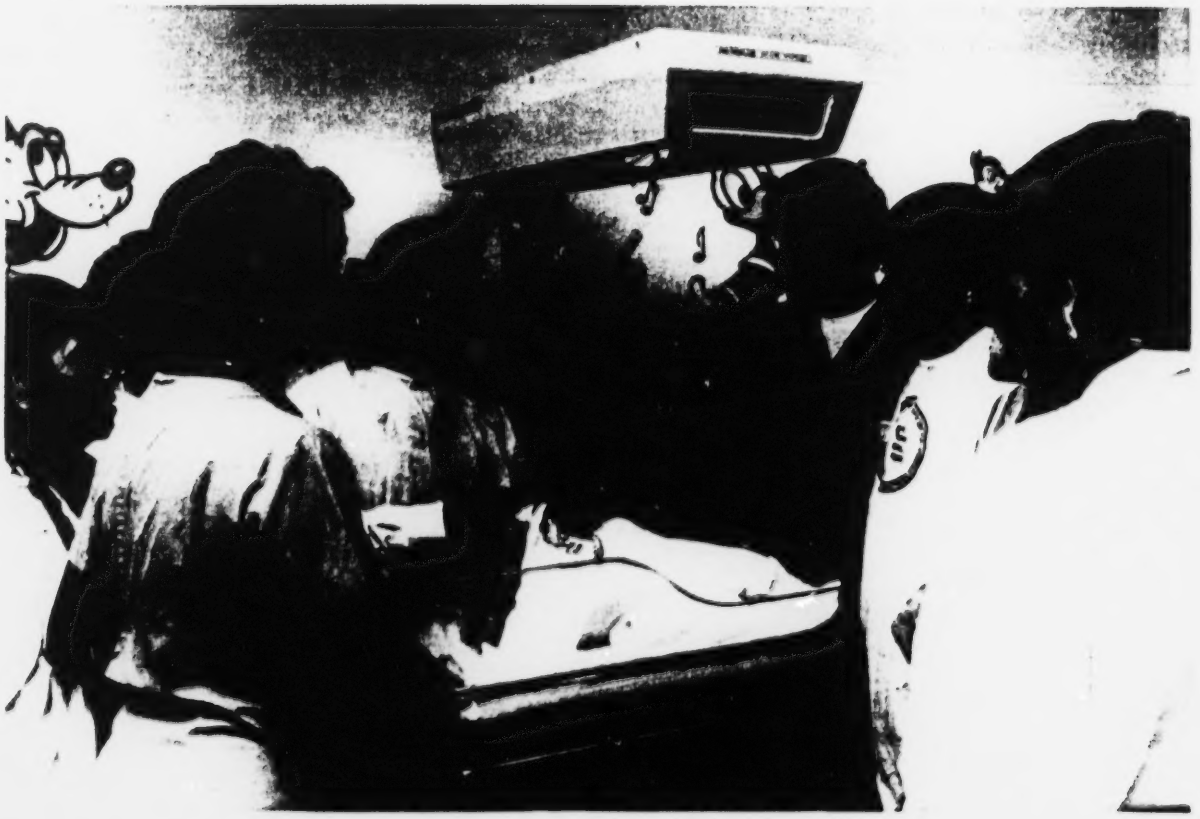
Interdisciplinary-Interagency Training for Professionals Serving Chemically Dependent Families



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It is estimated that, nationally, five million women of childbearing age use illicit drugs (GAO, 1990). Typically, women report polysubstance abuse, with alcohol among the substances of abuse. Fetal Alcohol Syndrome, a consequence of prenatal ethanol abuse, affects one out of every 750 births, and this is comparable to the number of children born each year with Down's syndrome (March of Dimes, 1989). The exact number of drug-affected infants born each year has been more difficult to determine. A recent survey of thirty-six selected hospitals nationwide found that 11 percent of all newborns had been exposed to illicit substances at some time during gestation (Chasnoff et al., 1989). In individual cities, estimates of the percentage of drug-involved births range from 7 percent in San Francisco and 7–1/2 percent in Washington, D.C., to 10–15 percent in Milwaukee and 16 percent in Philadelphia (Feig, 1990).

This startling national escalation in the incidence of prenatal substance abuse has occurred at a time when the deleterious effects on children of chemical dependency during pregnancy have become increasingly apparent. During the past decade, teratogenic and behavioral effects have been found with even moderate alcohol consumption during pregnancy (Landesman-Dwyer et al., 1978 and 1981), and in longitudinal studies of children of alcoholic mothers, mental retardation, neurologic impairments, growth retardation, and behavioral disorders have been well documented (Day et al., 1990; Fisher and Karl, 1988; Streissguth et al., 1981, 1989, and 1991). As women have increasingly begun to abuse drugs as well as alcohol, research efforts also have more clearly identified the medical complications and neurobehavioral problems associated with prenatal exposure to illicit drugs of abuse such as heroin, cocaine, methamphetamine, and phencyclidine (PCP) (Dixon and Bejar, 1989; Fulroth et al., 1989; Howard et al., 1986; Hoyme et al., 1990; Zuckerman et al., 1989).

During early infancy, many babies born to addicted mothers will continue to have significant feeding and sleeping problems. Some infants exposed prenatally to heroin and/or methadone will have gastrointestinal problems and will exhibit excessive movements that burn up calories and contribute to poor growth and weight gain during the first year. More recently, it has been noted that some infants exposed prenatally to cocaine and methamphetamine demonstrate a different pattern of feeding and sleeping difficulties. These babies frequently have hyperphagia (excessive sucking and swallowing as if from extreme hunger) compounded by uncoordinated sucking, resulting in poor weight gain. Protracted, high-pitched cries, frantic sucking of fists, tremors, and inability to organize normal sleep-wake cycles also are commonly observed. These prolonged "withdrawal" behaviors can disrupt family life and exhaust caregivers.

For traditional early intervention programs, providing effective and appropriate services for this growing special-needs population of parents has proven problematic. Often it is a challenge to engage biological families in conventional treatment programs, and the chemically dependent life-style makes long-term follow-up difficult. Families may request referrals and resources, fully intending to seek assistance and treatment, but lack of follow-through is common, and motivation for seeking treatment frequently is temporary. Parents may not use traditional systems, or may use these systems inappropriately. Moreover, intervention with chemically dependent families often is further complicated because professionals have limited understanding of the infants' medical and developmental needs and lack knowledge about addiction and its ramifications for parenting.

Model Demonstration and Outreach Projects

In 1985, as a result of our growing awareness of the problem of chemical dependency among pregnant women and the lack of appropriate services for this high-risk population of infants and parents, our staff began developing a comprehensive in-home early intervention program to serve drug- and alcohol-affected children and their caregivers. Original funding for this program was provided by the U.S. Department of Education, Handicapped Children's Early Education Program (HCEEP). Since 1988, ongoing support for this model program has been provided through funding from the Los Angeles County Board of Supervisors.

The staff of this in-home project is comprised of physicians, public health nurses, social workers, and early childhood educators. From the onset we recognized that no single discipline

could adequately address the chemically dependent family's complex array of special needs. Thus, in working with families, we have utilized an interdisciplinary team approach that relies heavily upon our staff's combined training and experience in the related fields of pediatric disabilities, early childhood education, maternal-child health, chemical dependency, and child abuse.

As previously reported, during its first three years of operation, our model project demonstrated that drug- and alcohol-affected infants and their caregivers could benefit from a comprehensive, coordinated plan of service delivery (Howard and Kropenske, 1989). The interagency-interdisciplinary approach we developed for serving families enabled us to maintain contact and build ongoing relationships with a traditionally difficult population, as well as insure continuity in developmental, health care, and social services for family members.

Encouraged by this success, in 1988 we began to replicate our model program throughout California through a HCEEP Statewide Outreach Program (1988-1991).

Statewide Outreach Training Program

The goals of our outreach program are:

1. to enhance professional understanding of the unique medical, developmental, environmental, educational, and physical care needs of substance-exposed infants and children, as well as the special medical, social, and environmental problems of chemically dependent parents and families; and

2. to assist public and private agencies in the development of local strategies and service delivery models of collaboration that promote coordinated, interdisciplinary-interagency case planning, management, and intervention for this at-risk population.

Within California, as in many other states, five separate agencies are actively involved in providing services for chemically dependent infants and families. Legal responsibility for coordinating services to the vast majority of this population is borne by the Department of Social Services, because in California the State Child Abuse Law requires that substance-affected infants be reported to local child protection agencies when there is evidence suggesting possible child endangerment. Additionally, the Department of Health Services, the Department of Alcohol and Drug Programs, the Department of Developmental Services, and the Office of the Superintendent of Schools each have mandated programs that serve large numbers of prenatally drug-exposed infants, their families, and their caregivers.

Over the past two and one-half years, our outreach efforts have targeted these major public agencies as we have introduced the model of interagency-interdisciplinary teamwork on a countywide basis. To date, our outreach efforts have involved twenty-one California counties, reaching over 1,200 administrators and clinicians from the disciplines of special education, developmental disabilities, nursing, social services, medicine, substance abuse treatment, and law.

Curriculum

Our interdisciplinary-interagency training consists of a two-day core workshop for local direct service providers and administrators and provides information regarding:

- medical, developmental, and psychosocial characteristics of chemically dependent infants and families;
- special service needs of this population;
- effective intervention strategies for managing their complex health, social, and educational problems;

- paradigms for evaluating child and family progress; and
- strategies for developing local interdisciplinary and interagency collaboration in case planning and management efforts.

Further, the workshops provide an opportunity for trainees who work within a common geographic area to become familiar with each other's roles, responsibilities, and competencies.

Because needs and interests vary within each county, the exact content and format of each workshop is flexible and tailored to meet specified needs of local agencies and trainees. We have found that, in some communities, agencies are highly experienced in providing services to chemically

dependent families, while in other areas of the state, agencies have little knowledge of the problems of either the parents or the children. Likewise, some communities already have developed strong interagency models for delivering services to substance abusing families, while others are just beginning this process.

Therefore, in developing the workshop content it has been important first to assess local case management and service delivery systems, as well as the knowledge base of community trainees. The establishment of a local planning committee comprised of key agency directors and administrative staff within each county has been pivotal to this process. It has been the responsibility of these committees to assist with trainee identification and selection, plan and critique training content, provide logistical support for the two-day workshop and, following training, to implement new interagency policies for serving substance abusing families.

In general, the content of the workshop has been as follows:

Day 1 Theme:

Medical and Developmental Issues

- *Overview of the problem:* national and local statistics on substance abuse and introduction to the interdisciplinary-interagency approach to case management
- *Substances of abuse*: local patterns and trends of illicit substance abuse and effects of various substances of abuse on the adult user
- *Medical and neurobehavioral sequelae*: effects of prenatal substance abuse on the mother, the fetus, the newborn, and the young child
- *Developmental patterns*: cognitive, language, motor, and personal-social development of infants and children; intervention strategies

Day 2 Theme:

Psychosocial and Staff Development Issues

- *Family dynamics and intervention implications*: the disease of chemical dependency, psychosocial and parenting issues for women substance abusers, treatment strategies
- *Working with parents, foster parents, and relative caregivers:* developing clinical competencies in interviewing, assessment, intervention, and interagency collaboration; staff attitudes and feelings in working with substance abusers
- *Interagency collaboration*: methods for fostering open communication and collaboration, developing a local approach to interdisciplinary case management

Subsequent to these workshop presentations, follow-up consultation and technical assistance is provided for individual counties and agencies over a six-month period.

Evaluation

Our Statewide Outreach program currently is in its third and final funding year. At this point, a multi-faceted program evaluation has been conducted that includes: (1) a pre-training survey to establish baseline interdisciplinary contact patterns; (2) a post-then knowledge acquisition survey (a variant of the pre-post method); (3) a training reaction instrument; (4) a mailed follow-up survey to gauge long-term changes in interdisciplinary practice patterns and the perceived utility of the training content; and (5) a case study of organizational change in several counties.

While the final evaluation is still underway, our data thus far support the following conclusions.

1. *Increased trainee knowledge*

Evaluation data on 473 second-year trainees indicate that participants' knowledge increased significantly in the following areas: (1) "street-wise" drug knowledge; (2) drug abuse intervention knowledge; (3) knowledge about substance-exposed infants; and (4) knowledge of intervention with substance-abusing families. On an average, individuals rated their knowledge prior to training as being in the "moderate" range, while they rated their knowledge after training as falling in or close to the "good" range. Moreover, follow-up data on over 200 trainees at six months have demonstrated the sustained impact of this program. When re-surveyed, respondents strongly reported that the training had given them information relevant to their provision of comprehensive services for substance-abusing parents and their children. This positive finding has been further validated by anecdotal reports from agency administrators and supervisors who have observed improved job performance among staff members who participated in both training and follow-up consultation activities.

2. *Enhanced interagency collaboration*

Within individual counties, the technical assistance provided by project staff has been instrumental in increasing collaboration among agencies, as demonstrated by the development of formal interagency protocols in six counties and the implementation of experimental interagency case management systems in fourteen counties. Further, follow-up survey respondents report that they are involved in a greater number of interagency/interdisciplinary contacts. Change data from baseline to follow-up on reported contact patterns, however, reveal only slight gains in this area. In light of how recently the training was conducted and subsequently developed interagency protocols were implemented, coupled with the difficulty of achieving such fundamental organizational changes in practice, this relatively small increment of change is nonetheless encouraging.

3. *Unmet Needs*

Three issues have emerged from our Outreach evaluation thus far. These are: (1) the need for additional skill-building for professionals who already have a basic knowledge of this sub-specialty area; (2) the need for further intervention at an agency level to sustain fundamental changes in interdisciplinary practice; and (3) the need to develop a mechanism whereby administrators and clinicians from other parts of the country can participate in didactic training, observe our in-home program and clinic activities, and receive technical assistance to support the development of collaborative programs within their own agencies and communities. We hope to be able to address these needs by expanding our outreach approach to include a national focus and to add an intensive skill-building component to the existing didactic training format.

Conclusion

P.L. 99–457 was enacted to expand and improve early intervention services for young children with disabilities and at-risk infants and toddlers. The interdisciplinary-interagency training we have conducted in California supports these efforts by helping to prepare professionals from a variety of disciplines to work more effectively with the growing population of high-risk drug- and alcohol-affected children. By providing local professionals with a common knowledge base and a common framework for working with families, training has promoted enhanced interagency collaboration and improved services for substance-affected infants and children throughout our state.

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Policy Implementation of Services for Infants and Toddlers with Developmental Delays

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For the past three decades, the federal government has tried,through a wide variety of legislative initiatives, to provide support for young children who have received a poor start in life. These include children from deprived economic circumstances and children with a variety of disabling conditions. The latest of these legislative initiatives is Part H of the Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act. Part H of this law provides planning and development funds for states to develop a comprehensive, multidisciplinary, interagency service system to serve infants and toddlers with developmental delays and their families. This article will describe some of the forces at work in implementing that legislation.

Since public policies are "the rules and standards by which we allocate scarce resources," such policies are one way in which a community, or a state or a nation, can establish its priorities and display its values. Public policy is also a way of stating a political hypothesis—that spending money in a particular way will achieve a predictable societal result, or that establishing certain rules and standards will ensure that particular consequences will follow. The development of the relatively new field of policy research is, in fact, one way of trying to test these political hypotheses.

Before a federal law becomes operational at the local level, it must pass through many individual and institutional hands. In that process, there is the opportunity for many changes and interpretations to be made. These changes and interpretations can shift the emphasis or focus of the law from its original intent. Is the legislative intent, expressed by the authors of the legislation, actually being observed when the law becomes operational at the local level, and what is the process by which a complex piece of legislation becomes translated into a practice? Until about a decade ago, the task of studying such issues rested largely in the hands of political scientists and economists.

With increased interest in social progress, and in what the federal government can do to improve services, the process of legislative implementation became a central issue for a variety of professionals and investigators. IDEA, if successfully implemented, will close the

circle of federal legislation for services for children with disabilities that began in 1958 with small amounts of money for research on educating children who were mentally retarded, and for training fellowships for teachers of children who were deaf or children who were mentally retarded. From this small beginning, a cornucopia of statutes supporting research, personnel preparation, demonstration projects, technical assistance, and direct aid to states has flowed from the nation's capitol.

Part H of IDEA covers an age group that previously had not been included in federal legislation prior to 1986, although developmental psychologists, health professionals, and special educators have long felt that the period from birth through three years is a critical one for the child and family to gain assistance in coping with difficult circumstances and developmental delays. In this law, the Congress attempts to recognize the diversity among states by providing a framework, or set of parameters, within which the states must operate, but gives considerable freedom to the states as to how that operation will take place within their own boundaries.

For example, in this "freedom within structure," the federal law calls for a child-find system, a set of standards for personnel preparation, a clear definition of who is developmentally delayed, and a system of coordinated finances, etc., but in each instance allows the state considerable leeway in terms of how each of these requirements is met. The law requires that a lead agency be identified by the governor of the state to manage the multidisciplinary and interagency resources needed to carry out this program but, again, the governor is free to choose the agency deemed most appropriate. In more than twenty states, the governors have identified the Department of Human Resources and Health as the lead agency. Currently, in eighteen states, the governors have chosen the Department of Education as the lead agency. In the other states, a variety of choices were made for the lead agency, for example the Developmental Disabilities Division, the Department of Mental Health, or the Governor's Office.

The problem of policy implementation was complicated by the clear intent of the law to institute certain major reforms in existing service practices. In this regard, it is similar to P.L. 94–142, the Education for All Handicapped Children Act, which, in addition to providing major resources for states to provide services to children with disabling conditions, required an individualized education plan, a nondiscriminatory evaluation, parental input into educational planning for their child, procedures for due process, the delivery of services in the least restrictive environment, etc. These two laws proposed to change the ways in which institutions and many different professions interact with their clientele—the child and the family. Such policies as the individualized education program and multidisciplinary assessments have changed, fundamentally, how professionals interact with their clients.

In a similar fashion, Part H of IDEA mandates a variety of conditions that the states must follow in the development of their comprehensive service systems. Among these are the requirements of the involvement of at least ten separate professional disciplines, the development of rules and standards for an individualized family service plan, the development of a set of personnel standards for professionals working with infants and toddlers, and a coordinated set of finances to support this program. These requirements introduce a set of new, and sometimes contradictory, conditions to what had previously been present in the states and, thus, complicates the planning and development process for each state. In recognition of the complexities of this law, the states were given four years to reach the level at which the plans would be completed and in operation, with full services expected to be provided at the beginning of the fifth year.

Policy Study

Because of the complexity of this law, the Department of Education entered into a cooperative agreement with the Carolina Policy Studies Program (CPSP), at the University of North Carolina at Chapel Hill, to track the implementation of this law in the fifty states, plus the District of Columbia. Beginning in 1988 and continuing into 1991, data were collected in an effort to answer two major questions: "How is this implementation proceeding in the states?" and "What factors allowed some states to be more rapid than others in reaching the level of full implementation?"

The CPSP identified three major phases in which the policy implementation would take place in Part H of IDEA: development, approval, and application. The first stage, which many states found most difficult, was policy development—the establishment of the written rules and standards by which these various requirements (e.g., individualized family service plan) were established.

Policy development was seen as follows:

Stage I—Policy Development

Policy development is defined as the generation of a set of written rules and procedures which guide the allocation of resources, identify the eligible candidates for the special services, delineate the system of services, identify who will deliver the services, and state the conditions under which the services will be delivered.

One of the clear necessities in policy development is to achieve some type of consensus, among the various powerful and influential circles in the state, regarding the fourteen required components. The institutions charged with the responsibility of carrying out this law, such as the lead agency or the Interagency Coordinating Council, have quickly discovered that they had been given responsibility without essential power or authority. It is one thing to mandate the lead agency to coordinate finances for this program across multiple state agencies; it is another to convince persons in the other agencies to share their resources for this particular program.

The second major phase of policy implementation, as identified by the Carolina Policy Studies Program, is obtaining policy approval.

Stage II—Policy Approval

This phase reflects the series of actions and events necessary to obtain support or official sanction for the policies that have been developed. In some states this may mean necessary action by the state legislature; in others, it may mean action by the governor, and in still others, actions taken by the lead agency. Some definitive action is necessary, however, before "draft" policies become the official policy of the state.

It became clearly evident to some of the more successful state policy makers that one has to begin planning for the policy approval stage while still working on the development of written policies. The inclusion of a variety of agency personnel, key legislators, or advocacy groups in the policy development process clearly laid the groundwork for an easier process of policy approval.

The final stage, policy application, is one that few states have yet reached.

Stage III—Policy Application

Once the policies have been given an official sanction it is then necessary to implement them at the state level as well as the local level where the actual service delivery takes place. At this point, it is necessary to determine if these rules are appropriate to the specific problems posed by both the state and local environments.

The process of actually putting these state policies into operation should, undoubtedly, yield valuable information on how practical and useful the policies were in the first place and will, no doubt, result in continued modification of the policies to more effectively meet local conditions.

Carolina Policy Studies Program Findings

Through surveys, the use of rating scales, content analysis of documents, telephone interviews, focus group discussions, and case studies of individual states, the CPSP has tried to answer the two fundamental questions: *What is happening in policy implementation and why is it happening?*

The following represent some of the major findings from several Carolina Policy Studies Program reports. A full listing of these reports is available from the Carolina Policy Studies Program, University of North Carolina at Chapel Hill, 137 E. Franklin St., Chapel Hill, NC 27514.

Overall State Progress

For over four years, the states have made meaningful progress toward fulfilling policy development for the fourteen components required by Part H of IDEA. The ability to write a definition of the eligible population and the establishment of policies for the development of the Individualized Family Service Plan (IFSP) were among those closest to completion, while the development of interagency agreements and the coordination of finances lagged behind the other components.

States were far less advanced in policy approval or policy application than in policy development because of the serious problems of state financing and the time-consuming nature of joint decision making, but as a result of the reauthorization process, were given two more years to complete their work.

States that had developed an administrative structure and process for policy development across agencies have made more progress in the implementation of Part H of IDEA than those states that had not developed such a process.

Eligibility

States have made considerable progress toward developing a definition of "developmentally delayed." Only eleven states are still considering the inclusion of "at-risk" children in the definition at this time.

Policy analysis revealed three main approaches used by forty-two reporting states that included specific criteria for determining eligibility for developmentally delayed infants and toddlers: (1) use of test-based criteria only (e.g., 25 percent delay) (N=16); (2) use of professional judgement and/or the documentation of atypical development only (N=4); (3) or a combination of professional judgement and the use of test-based criteria (N=22).

Personnel Preparation

Enormous shortages exist in many professions, suggesting that new models

PART H Reauthorization Signed by President Bush

On October 7, 1991, President Bush signed the reauthorization legislation for Part H of the Individuals with Disabilities Education Act (IDEA), the program for Infants and Toddlers with Disabilities and their Families. Originally enacted in 1986 as P.L. 99–457, the Individuals with Disabilities Education Act of 1991 (P.L. 102–119)

- improves procedures for ensuring that American Indian children with disabilities and their families receive early intervention services under Part H;
- provides new authority to establish statewide, interagency systems for the identification, tracking, and referral to appropriate services for all children who are at risk of having developmental delays;
- authorizes up to five personnel training grants to support the creation of partnerships between public and private entities to provide opportunities for career advancement and competency-based training for professionals in the field of special education;
- strengthens participation of and control by families of the services and supports they receive through the Part H program;
- streamlines the transition process between the Part H program and the preschool program;
- encourages the provision of services to infants and toddlers with disabilities in natural environments; and,
- includes assistive technology services and devices as a specifically authorized early intervention service.

of service delivery are required. Personnel attrition studies in early childhood programs suggest that more than 50 percent of staff will turn over in a three-year period.

Deans of Schools of Education surveyed were not willing to commit resources to early education personnel unless there were financial incentives, certification requirements, etc.

Professional associations were generally not going to add additional requirements for certification, but some were settling for statements of "best practice" for this age group.

Finance

States are concentrating the majority of their finance efforts on a small number of sources, even if there are fifteen or more sources that might be theoretically available.

Successful states tend to use a core of state funds to build a broader financial plan for comprehensive services.

Medicaid may provide one important source of funding that states can use for infant and toddler services. Private insurance may be another.

Family

The most common method for identification of family needs was the informal interview; more structured assessments was the next most frequent choice.

The majority of states plan to use an interim service coordinator for the process of multidisciplinary assessment and IFSP development. An operational service coordinator will be assigned by the IFSP team when the IFSP is developed.

Most of the states appear to be making a "good faith" effort to meet the requirements for involvement of families in decision making for their child.

Health Coordination

Physician members of the state Interagency Coordinating Committees (ICCs) were strongly in favor of including biologically "at risk" and environmentally "at risk" children in the population to be served.

Focus group interviews revealed a variety of barriers to effective health services, including: uneven distribution of resources, personnel shortages, transportation problems, excessive paper work, "inner city" and "rural" settings that interfered with good health practices, and difficulties in coordinating multidisciplinary care.

Interagency Coordination

States were at different levels (ranging from beginning to advanced) in the development of a process for interagency service provision.

States varied as to the major purposes selected for the coordination of services, which were to: (a) coordinate a single aspect of the service system for developmentally delayed infants and toddlers; (b) coordinate all services for developmentally delayed children in order to achieve uniformity across programs and agencies; (c) coordinate services for developmentally delayed and at-risk children; and, (d) coordinate all programs for all young children.

The successful development of interagency service coordination usually required the interaction of several broad factors: (1) a climate within the state conducive to coordination; (2) leadership of key people across agencies, (3) an administrative structure and processes to facilitate coordination; (4) a systematic and coordinated state planning process; and, (5) financial resources earmarked to carry out the planning of the interagency process and the interagency system.

The availability of multiple structures and mechanisms within the state to facilitate joint decision-making would entail the use of such mechanisms as: cross-disciplinary task forces to achieve certain policy goals; the use of consultants from outside the state who could bring ideas regarding strategies to obtain collaboration; the use of project staff to serve as liaisons between the Part H program and relevant state agencies; and, the availability of organizational structures, such as a State Commission on Children and Youth, that provided a continuing policy input into both the executive and legislative branches.

One of the elements for effective policy development across all aspects of Part H identified by various CPSP staff is the concept of "shared vision." That is, a conceptualization of just how this comprehensive, coordinated service system would operate at state and local levels. A significant part of this "shared vision" is also a clear understanding of how the state will get from the current service configuration to the goal of comprehensive services. This vision, shared by key individuals from a variety of agencies and constituencies, is critical to the ability of the state to make progress in the implementation of this revolutionary legislation.

Barriers to Implementation

In each of the states that were picked out for intensive case study, barriers to implementation had to be overcome. Many of these barriers were psychological in nature, involving suspicions of the motivations of others, the concern about the self-interest of various individuals, or the self-interest of the organizations that the individuals represented. Interagency agreements must face the concern that "my agency" may be having its resources diverted to meet the priorities of some other agency—a highly inhibiting viewpoint, if strongly held. Lack of money, the threat of recession, and competing state programs were also strong inhibitors.

Perhaps one of the more subtle problems was the sheer volume of the changes expected. To change family policy, personnel standards, interagency relationships, financial patterns, child find systems, and health-education coordination, all at the same time, raised some serious problems that each of these requirements might not have presented if each were considered by itself.

It would seem that many of the facilitators and inhibitors of policy implementation that have been observed in Part H of IDEA are generic in nature and would be present in the implementation of any future multiagency legislation. It would be wise for the framers of future legislation to reflect on these facilitators and inhibitors of policy implementation as they plan the next legislative initiative. ♦

AN OSERS NEWS IN PRINT SPECIAL SECTION ON
ATTENTION DEFICIT DISORDERS

A Clarification of State and Local Responsibility under Federal Law to Address the Needs of Children with Attention Deficit Disorders

The following statement is excerpted from the policy memorandum issued by the U.S. Department of Education on September 16, 1991 and signed jointly by the assistant secretaries for the Office of Special Education and Rehabilitative Services, the Office for Civil Rights, and the Office of Elementary and Secondary Education.

I. Introduction

The purpose of this statement is to clarify the circumstances under which children with ADD are eligible for special education services under Part B of the Individuals with Disabilities Education Act (Part B), as well as the Part B requirements for evaluation of such children's unique educational needs. This statement will also clarify the responsibility of state and local education agencies (SEAs and LEAs) to provide special education and related services to eligible children with ADD under Part B. Finally, this statement clarifies the responsibilities of LEAs to provide regular or special education and related aids and services to those children with ADD who are not eligible under Part B, but who fall within the definition of "handicapped person" under Section 504 of the Rehabilitation Act of 1973.

II. Eligibility for Special Education and Related Services Under Part B

Last year during the reauthorization of the Education of the Handicapped Act, renamed the Individuals with Disabilities Education Act (IDEA), Congress gave serious consideration to including ADD in the definition of "children with disabilities" in the statute. The Department took the position that ADD does not need to be added as a separate disability category in the statutory definition since children with ADD who require special education and related services can meet the eligibility criteria for services under Part B. This continues to be the Department's position.

A. Description of Part B

Part B requires SEAs and LEAs to make a free appropriate public education (FAPE) available to all eligible children with disabilities and to ensure that the rights and protections of Part B are extended to those children and their parents (20 U.S.C. 1412(2); 34 CFR §§300.121 and 300.2). Under Part B, FAPE, among other elements, includes the provision of special education and related services, at no cost to parents, in conformity with an individualized education program (IEP) (34 CFR §300.4).

In order to be eligible under Part B, a child must be evaluated in accordance with 34 CFR §§300.530-300.534 as having one or more specified physical or mental impairments, and must be found to require special education and related services by reason of one or more of these impairments (20 U.S.C. 1401(a)(1); 34

CFR §300.5). SEAs and LEAs must ensure that children with ADD who are determined eligible for services under Part B receive special education and related services designed to meet their unique needs, including special education and related services needs arising from the ADD. A full continuum of placement alternatives, including the regular classroom, must be available for providing special education and related services required in the IEP.

B. Eligibility for Part B Services Under the "Other Health Impaired" Category

The list of chronic or acute health problems included within the definition of "other health impaired" in the Part B regulations is not exhaustive. The term "other health impaired" includes chronic or acute impairments that result in limited alertness that adversely affects educational performance. Thus, children with ADD should be classified as eligible for services under the "other health impaired" category in instances where the ADD is a chronic or acute health problem that results in limited alertness, which adversely affects educational performance. In other words, children with ADD, where the ADD is a chronic or acute health problem resulting in limited alertness, may be considered disabled under Part B solely on the basis of this disorder within the "other health impaired" category in situations where special education and related services are needed because of the ADD.

C. Eligibility for Part B Services Under Other Disability Categories

Children with ADD are also eligible for services under Part B if the children satisfy the criteria applicable to other disability categories. For example, children with ADD are also eligible for services under the "specific learning disability" category of Part B if they meet the criteria stated in §§300.5(b)(9) and 300.541 or under the "seriously emotionally disturbed" category of Part B if they meet the criteria stated in §300.5(b)(8).

III. Evaluations under Part B

A. Requirements

SEAs and LEAs have an affirmative obligation to evaluate a child who is suspected of having a disability to determine the child's need for special education and related services. Under Part B, SEAs and LEAs are required to have procedures for locating, identifying, and evaluating all children who have a disability or are suspected of having a disability and are in need of special education and related services (34 CFR §§300.128 and 300.220). This responsibility, known as "child find," is applicable to all children from birth through twenty-one, regardless of the severity of their disability.

Consistent with this responsibility and the obligation to make FAPE available to all eligible children with disabilities, SEAs and LEAs must ensure that evaluations of children who are suspected of needing special education and related services are conducted without undue delay (20 U.S.C. 1412(2)). Because of its responsibility resulting from the FAPE and child find requirements of Part B, an LEA may not refuse to evaluate the possible need for special education and related services of a child with a prior medical diagnosis of ADD solely by reason of that medical diagnosis. However, a medical diagnosis of ADD alone is not sufficient to render a child eligible for services under Part B.

Under Part B, before any action is taken with respect to the initial placement of a child with a disability in a program providing special education and related services, "a full and individual evaluation of the child's educational needs must be conducted in accordance with requirements of §300.532" (34 CFR §300.531). Section 300.532(a) requires that a child's evaluation must be conducted by a multidisciplinary team, including at least one teacher or other specialist with knowledge in the area of suspected disability.

B. Disagreements over Evaluations

Any proposal or refusal of an agency to initiate or change the identification, evaluation, or educational placement of the child, or the provision of FAPE to the child is subject to the written prior notice requirements of 34 CFR §§300.504-300.505. If a parent disagrees with the LEA's refusal to evaluate a child or the LEA's evaluation and determination that a child does not have a disability for which the child is eligible for services under Part B, the parent may request a due process hearing pursuant to 34 CFR §§300.506-300.513 of the Part B regulations.

IV. Obligations Under Section 504 of SEAs and LEAs to Children with ADD Found Not To Require Special Education and Related Services under Part B

Even if a child with ADD is found not to be eligible for services under Part B, the requirements of Section 504 of the Rehabilitation Act of 1973 (Section 504) and its implementing regulation at 34 CFR Part 104 may be applicable. Section 504 prohibits discrimination on the basis of handicap by recipients of Federal funds. Since Section 504 is a civil rights law, rather than a funding law, its requirements are framed in different terms than those of Part B. While the Section 504 regulation was written with an eye to consistency with Part B, it is more general, and there are some differences arising from the differing natures of the two laws. For instance, the protections of Section 504 extend to some children who do not fall within the disability categories specified in Part B.

A. Definition

Section 504 requires every recipient that operates a public elementary or secondary education program to address the needs of children who are considered "handicapped persons" under Section 504 as adequately as the needs of nonhandicapped persons are met. "Handicapped person" is defined in the Section 504 regulation as any person who has a physical or mental impairment which substantially limits a major life activity (*e.g.*, learning) (34 CFR §104.3(j)). Thus, depending on the severity of their condition, children with ADD *may* fit within that definition.

B. Programs and Services Under Section 504

Under Section 504, an LEA must provide a free appropriate public education to each qualified handicapped child. A free appropriate public education, under Section 504, consists of regular or special education and related aids and services that are designed to meet the individual student's needs and based on adherence to the regulatory requirements on educational setting, evaluation, placement, and procedural safeguards (34 CFR §§104.33, 104.34, 104.35, and 104.36). A student may be defined as handicapped within the meaning of Section 504, and therefore entitled to regular or special education and related aids and services under the Section 504 regulation, even though the student may not be eligible for special education and related services under Part B.

Under Section 504, if parents believe that their child is handicapped by ADD, the LEA must evaluate the child to determine whether he or she is handicapped as defined by Section 504. If an LEA determines that a child is not handicapped under Section 504, the parent has the right to contest that determination. If the child is determined to be handicapped under Section 504, the LEA must make an individualized determination of the child's educational needs for regular or special education or related aids and services (34 CFR §104.35). For children determined to be handicapped under Section 504, implementation of an individualized education program developed in accordance with Part B, although not required, is one means of meeting the free appropriate public education requirements of Section 504. The child's education must be provided in the regular education classroom unless it is demonstrated that education in the regular environment with the use of supplementary aids and services cannot be achieved satisfactorily (34 CFR §104.34).

Should it be determined that the child with ADD is handicapped for purposes of Section 504 and needs only adjustments in the regular classroom, rather than special education, those adjustments are required by Section 504. A range of strategies is available to meet the educational needs of children with ADD. Regular classroom teachers are important in identifying the appropriate educational adaptions and interventions for many children with ADD.

SEAs and LEAs should take the necessary steps to promote coordination between special and regular education programs. Steps also should be taken to train regular education teachers and other personnel to develop their awareness about ADD and its manifestations and the adaptations that can be implemented in regular education programs to address the instructional needs of these children. Examples of adaptations in regular education programs could include the following:

> *providing a structured learning environment; repeating and simplifying instructions about in-class and homework assignments; supplementing verbal instructions with visual instructions; using behavioral management techniques; adjusting class schedules; modifying test delivery; using tape recorders, computer-aided instruction, and use of other audio-visual equipment; selecting modified textbooks or workbooks; and tailoring homework assignments.*

Other provisions range from consultation to special resources and may include reducing class size; use of one-on-one tutorials; classroom aides and note takers; involvement of a "services coordinator" to oversee implementation of special programs and services; and possible modification of nonacademic times such as lunchroom, recess, and physical education.

Through the use of appropriate adaptations and interventions in regular classes, many of which may be required by Section 504, the Department believes that LEAs will be able to effectively address the instructional needs of many children with ADD.

C. Procedural Safeguards Under Section 504

Procedural safeguards under the Section 504 regulation are stated more generally than in Part B. The Section 504 regulation requires the LEA to make available a system of procedural safeguards that permits parents to challenge actions regarding the identification, evaluation, or educational placement of their handicapped child who they believe needs special education or related services (34 CFR §104.36). The Section 504 regulation requires that the system of procedural safeguards include notice, an opportunity for the parents or guardian to examine relevant records, an impartial hearing with opportunity for participation by the parents or guardian and representation by counsel, and a review procedure. Compliance with procedural safeguards of Part B is one means of fulfilling the Section 504 requirement.

However, in an impartial due process hearing raising issues under the Section 504 regulation, the impartial hearing officer must make a determination based upon that regulation.

OSEP's Initiatives for Meeting the Needs of Children with Attention Deficit Disorders

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Background

In recent years, practitioners and researchers in education, medicine, and psychology, as well as parents, have called attention to the importance of identifying and serving children with attention deficit disorders (ADD). In the education community particularly, there has been a growing concern that ADD can result in learning problems. Although research has been conducted on identification and intervention, this information has not been analyzed, organized, or communicated in a manner that is consistent or that is useful to educators and parents. As a result of growing concerns, Congressional actions, and U.S. Department of Education initiatives, this will change.

Attention deficit disorders are among the most frequent causes for referrals of children to mental health clinics in the United States, accounting for as many as 50 percent of all referrals to outpatient mental health clinics (LaGreca & Quay, 1984). Estimates of its prevalence in typical school-aged children range from as low as one percent to as high as 12 percent depending on how the disorder is defined, with most authoritative sources estimating it at approximately 3 percent (American Psychiatric Association, 1987; Barkley, 1981).

Children with attention deficit disorders are served primarily in the public schools. According to recent reports, however, school personnel find children with ADD difficult to teach (Virginia Department of Education, 1991). Children with ADD do not respond in the same way as other children to instructional and management techniques. They are often disruptive and are at risk for academic and social failure unless taught and managed appropriately. Children with attention deficit disorders present challenges to educators which must be met in the public schools. For most school personnel, however, information about ADD is not readily available; and the information that is available often is confusing and contradictory.

OSEP Activities

In Fiscal Year 1991, Congress appropriated funds for the Department of Education to synthesize and disseminate information on current knowledge about how to serve children with ADD. In response, the Office of Special Education Programs has designed two types of activities to meet the needs of children with ADD.

Organizing and Analyzing the Research Knowledge Base. Four centers have been funded to synthesize the existing research knowledge in assessment and interventions for meeting the needs of children with attention deficit disorders. These projects will engage in activities to increase the awareness of educators, researchers, and parents on the *research based interventions and assessment strategies* for children with attention deficit disorders. The centers will organize, synthesize, and disseminate the current research knowledge base on two topics: 1) assessment and identification of children with attention deficit disorders; and 2) interventions for children with attention deficit disorders. Each center will identify critical issues that demonstrate the greatest promise for educators, researchers, and parents to respond to the needs of children with ADD. Examples of the critical issues are:

- **Intervention:** nature of effectiveness of intervention techniques involving home and school; effect of pharmacological therapy on the success of other interventions; and influence of related problems, such as aggression, on the selection of intervention strategies.

- **Assessment and Identification:** theoretical assumptions underlying current definitions of ADD and the validity of the assumptions; types and procedures available and how assessment information is used to classify individuals having ADD; quality of existing instruments and procedures; and professional competencies required for evaluating individuals with ADD.

On October 1, 1991, two centers located at the University of Miami and at the Arkansas Children's Hospital Research Center began to address the

critical issues in assessing and identifying children and youth with attention deficit disorders.

The two centers at the University of California-Irvine and at Research Triangle Institute will address the critical issues for intervening with children and youth with attention deficit disorders. Additional information about the projects appears in Table 1.

Each center will engage parents, researchers, and educators in identifying the critical issues on teaching children with attention deficit disorders. The issues will provide the focus for the centers :

- organize and analyze the current research base; design, format, and synthesize information into useful products for educators, parents, and researchers;
- disseminate and exchange the information at the National Forum to parents, educators, and researchers; coordinate activities with the other centers; and
- disseminate the information through existing parent, professional, and national networks.

In January 1992, OSEP convened a meeting in Washington, D.C. for the project directors to identify and discuss the critical issues for assessing, identifying, and intervening with children with ADD. Each center will identify a set of critical issues by using strategies ranging from conducting mail or phone surveys to forming national focus groups of persons representing relevant targeted audiences. These critical issues will then be made available to the relevant audiences.

Subsequently, center staff and consultants will synthesize the research literature employing rigorous methodological procedures; design information products and materials for targeted audiences to communicate the findings from the syntheses; and communicate with targeted audiences through existing networks and professional organizations.

Identifying Successful Practices. The Federal Resource Center (FRC) at the University of Kentucky will identify successful practices and programs for serving students with ADD at the local and district level. In contrast to the centers synthesizing empirical research, the FRC will capture practices and programs that are *considered by practitioners to be successful* for meeting the needs of children with ADD. The Federal Resource Center will investigate promising practices and programs to meet the needs of children with attention deficit disorders. These promising practices and programs may appear at the local, district, or state level. Further, these promising practices will be summarized by the following areas:

- organizational and environmental conditions necessary for effective professional practice;
- instructional strategies and techniques;
- curricula and instructional tools, such as textbooks, media, and technology; and
- strategies and techniques to support family involvement.

The FRC has employed a stakeholder's approach for identifying and capturing the promising educational practices and programs. The stakeholders are comprised of teachers, administrators, parents, health care and family treatment professionals, and researchers who currently work with children with ADD and their families.

Initially, the stakeholders will develop a set of criteria for considering a practice or program to be successful. Subsequently, stakeholders will nominate sites that meet the criteria; FRC staff will make visits to the sites to identify specific materials and procedures; and finally, FRC staff will develop products to communicate the findings of the successful practices and programs for teachers, administrators, and parents.

In December 1992, the four centers and the FRC will present the analysis of their findings at a National Forum to be held in Washington, D.C. The Forum will provide an opportunity for the researchers to discuss with parents, educators, and policy makers, the outcomes from their activities.

Currently Funded Projects Designed to Meet the Needs of Children with Attention Deficit Disorders

CENTERS ON ORGANIZING AND ANALYZING THE RESEARCH KNOWLEDGE BASE:

INTERVENTION

Dr. James Swanson
University of California—Irvine
19262 Jamboree Blvd.
Irvine, California 92715
(714) 856–8730

Dr. Tom Fiore
Research Triange Institute
3040 Cornwallis Road
P.O. Box 12194
Research Triangle Park, NC
(919) 541–6004

ASSESSMENT AND IDENTIFICATION

Dr. James McKinney
University of Miami
P.O. Box 248065
Coral Cables, Florida 33124
(305) 284–5388

Dr. Roscoe Dykman
Department of Pediatrics
Arkansas Children's Hospital
Research Center
1120 Marshall Street
Little Rock, Arkansas
(501) 320–3333

IDENTIFYING SUCCESSFUL PRACTICES AND PROGRAMS:

Dr. Larry Carlson
Federal Resource Center
University of Kentucky
314 Mineral Industries Bldg.
Lexington, Kentucky 40506
(606) 257-1337

Attention Deficit Disorders Academic Functioning and Stimulant Medication

Steven R. Forness, Ed.D.

UCLA Department of Psychiatry and Biobehavioral Services

The study of children with attention deficit disorders (ADD) has been complicated by a variety of factors, particularly within special education. Although ADD has long been considered a subtopic of the field of learning disabilities (LD) within special education, more recent findings, including those in this article, suggest that relatively few children with ADD may actually qualify as having LD. This is especially true when discrepancy formulas used by most states as criteria for LD diagnostic eligibility are applied. The field of emotional or behavioral disorders in special education, on the other hand, rarely focuses its research on specific disorders, such as ADD, although such diagnostic disorders are very much a research focus in child psychiatry and psychology. Likewise problematic is the fact that ADD often co-occurs, or is co-morbid, with a variety of other specific psychiatric diagnoses, such as conduct disorders or childhood depression. Its principal symptoms of inattention, impulsiveness, and motor overactivity also frequently overlap similar symptoms found in a variety of other psychiatric disorders (Barkley, 1990).

Even within psychiatry or psychology, ADD is not an easy diagnosis to establish, nor is treatment for ADD clear-cut. There is, for example, a great deal of evidence that the diagnoses of ADD and conduct disorders are often inextricably intertwined (Werry, Reeves, Elkind, 1987). There is also a great deal of variability in cognitive and academic performance both between and within samples of ADD children (Goldstein, 1987), thus making it quite difficult to interpret research on this diagnosis. There is likewise a variety of expressions of ADD. Some children may present with symptoms in all three areas of inattention, impulsiveness, and hyperactivity; yet others may lack sufficient symptomatology in at least one of these areas (Henker & Whalen, 1989; Lambert, 1988). Finally, the treatment of hyperactivity is often interdisciplinary, with multimodality interventions used across home, school, and medical settings (Horn et al, 1991), and is frequently complicated by the fact that some subgroups of children with ADD may respond differently to treatment (Swanson, Cantwell, Lerner, McBurnett, & Hanna, 1991).

This article will describe preliminary data on special education issues from an interdisciplinary research program that has been conducted by James Swanson, a child psychiatrist from the University of California at Irvine, Dennis Cantwell, a child psychiatrist from my own department, and myself.

It should be pointed out, as most readers are aware, that ADD has recently become a particular focus in special education because of the pressure from advocacy groups to include ADD as a separate category for special education services (Parker, 1989). It is also clear that the cluster of symptoms that characterize children with ADD may represent a particularly large subtype within the learning disability category (Forness, 1990) and that ADD may be one of the most frequent psychiatric diagnoses in children ultimately found eligible for the category of serious emotional disturbance (SED) within special education (Mattison, Humphrey, Kales, Hernit & Finkenbinder, 1986). This article will note certain implications for eligibility in special education that have been a spin-off of this research project.

Methodologic Approach

This study includes eighty-two boys, ages seven to twelve, screened for ADD, in particular the diagnosis of attention deficit hyperactivity disorder (ADHD) as determined by DSM III-R criteria. Only boys have been used since it is still relatively unclear what kind of differences exist between boys and girls who have ADD. The diagnostic process is rather rigorous in that boys selected for the study had to pass through four "gates" in order to qualify for final selection. First, they had to be referred for suspected ADHD from larger clinic populations at a pediatric-based clinic at the University of California, Irvine, or an outpatient psychiatric clinic at UCLA. Two sites have been used to avoid referral bias. Second, they had to meet clinical cutoff scores for ADHD on the ten-item Conners Rating Scale (Conners, 1969). Third, they had to meet criteria for ADHD and/or conduct or oppositional disorders on the ten-item Iowa Conners Questionnaire (Loney & Millich, 1982). Fourth, they had to be diagnosed by a child psychiatrist using a structured, psychiatric diagnostic interview schedule. This interview is used both to rule in ADHD or conduct disorders and to rule out possible symptoms of other psychiatric disorders, such as depressed mood or hallucinations. Almost 14 percent of the referred study sample has not made it past all four gates. The total sample selected consists of seventy-one boys, of which thirty have presumably a "pure" diagnosis of only ADHD and forty-one have a diagnosis of ADHD plus a conduct or oppositional disorder, a "mixed" diagnosis. Neither group appears to have any other diagnoses such as depression, anxiety, or schizophrenic disorders.

One phase of the study deals with careful psychoeducational testing of each subject (Forness, Youpa, Hann, Cantwell, & Swanson, in press), another deals with response to rigorous, double-blind, placebo, crossover trials of stimulant medication (Forness, Cantwell, Swanson, Hanna, & Youpa, 1991) and the third deals with each subject's response to six weeks of sustained treatment with stimulant medication in each subject who is judged to be a responder in the medication trials (Forness, Swanson, Cantwell, Youpa, & Hanna, in press). Preliminary findings on medication trials suggest that "responder" status may range from 23 to 89 percent depending on which of six dependent measures is used to determine a therapeutic response to the stimulant used, methylphenidate (Ritalin); but only findings on response to two of the dependent measures relevant to special education will be reported in this article (Swanson, Cantwell, Forness, Taylor, Youpa, & Hanna, in press).

Preliminary Findings

Psychoeducational testing results are presented in Table 1 for the seventy-one subjects along with other related data. Testing has been done after subject selection but prior to any medication trials. IQ findings from the

Two Subgroups of 71 Boys With Attention Deficit Hyperactivity Disorder

Variable	Pure		Mixed	
	Mean	SD	Mean	SD
Number of Ss	30		41	
Percentage of minority Ss	9.6%		12.2%	
Age (years)	9.4	1.7	9.1	1.7
WICSC-R: Full scale IQ	107.1	16.3	105.0	14.2
Verbal IQ	106.4	17.6	102.6	15.3
Performance IQ	106.5	14.8	107.8	15.3
Attention cluster	8.9	2.5	8.8	2.6
Linguistic cluster	11.4	2.9	11.0	2.6
Perceptual cluster	11.3	2.4	11.2	2.6
PIAT reading recognition (grade level)	5.1	2.5	4.4	2.2
PIAT reading comprehension (grade level)	5.4	2.9	4.3	2.9
WRMT total (grade level)	4.8	2.8	3.6	1.8
PIAT arithmetic (grade level)	4.4	2.3	4.3	1.9
KMDT total (grade level)	4.7	2.3	3.6	1.6
Number meeting LD discrepancy formula of				
one standard deviation (SD)	1		3	
1.5 standard deviation (SD)	4		3	

Wechsler Intelligence Scale for Children—Revised (WISC-R), along with achievement screening subtest scores from the Peabody Individual Achievement Test (PIAT) and total diagnostic test scores from the Woodcock Reading Mastery Tests (WRMT) and the Key Math Diagnostic Test (KMDT) are given in Table 1. Also provided in the table are the WISC-R subtest cluster averages for attention (Arithmetic, Coding, and Digit Span subtests), linguistic (Vocabulary, Similarities, and Comprehension subtests), and perceptual (Picture Completion, Block Design, and Object Assembly subtests) clusters. A diagnosis of learning disability has also been made using Reading Recognition score from the PIAT and full scale IQ from the WISC-R, which is entered into a regression discrepancy formula adopted for use in California.

Note that both groups are relatively evenly matched on age, IQ, and minority status. Both groups also demonstrate an equal cognitive impairment in attention on IQ testing. The mixed ADHD group with conduct disorders, however, clearly seems at a disadvantage when it comes to academic performance. They seem to average about a semester or even a year below the pure ADHD group in virtually every academic area. These differences were only statistically significant in two instances, on the total KMDT score and one subtest (passage comprehension) score on the WRMT. The variability of scores was impressive in that IQs ranged from the level of mental retardation up to the gifted range and academic scores literally range from first to twelfth grade. Note that, when a strict discrepancy standard of 1.5 standard deviations is used to diagnose eligibility, less than six percent of the entire sample qualifies as LD. When the discrepancy criterion is relaxed to one standard deviation, still fewer than 15 percent of the total sample qualify as LD.

The medication trials involve each subject's undergoing a five-week series. Baseline measures of drug response have been administered in the first week; and, in each of the next four successive weeks, each subject receives a full week of treatment with methylphenidate at low (0.3 mg/kg), medium (0.6 mg/kg), or high (1.0 mg/kg) dose, along with a week of placebo. Each of these weeks involve doses at 7:30, 11:30, and 3:30 each day. These week-long trials are randomly assigned. Neither the subject, his parent, his teacher, nor the experimenters who administer the measures know which dose the child is on until after trials have been completed.

Once during each week, the subject is administered two tests of reading performance, along with a variety of other dependent measures. One involves oral reading of a fifty word passage, and the other involves reading a story of a few short paragraphs and answering ten multiple-choice comprehension questions on the topic. Each of these measures involve an alternate but equivalent form each week, and each form has been selected to represent each subject's approximate level of oral reading or reading comprehension performance, which is kept constant throughout all the trials to insure that basal or ceiling effects would not affect performance.

None of the results in oral reading have been found to be significant across any of the conditions. Subjects read about as well at placebo and baseline as they do while being treated with methylphenidate. They make about the same amount of errors and take about as long to read each paragraph across all conditions. Neither of the two groups differ from one another in their response to methylphenidate on oral reading. In reading comprehension, however, the findings are somewhat different. These results are provided in Table 2. Here both groups perform about the same at baseline, before medication trials began; and the mixed ADHD group remains almost the same while receiving placebo. The mixed group, however, seems to improve somewhat at all three levels of dose, while the pure ADHD group improves about as much with a placebo as they do with any of the three doses of methylphenidate. These results are statistically significant but barely fail to reach significance in this group after six weeks of treatment.

Means and Standard Deviations Across All Medication Conditions for Score on Reading Comprehension Measure.

Condition	Pure		Mixed	
	Mean	SD	Mean	SD
Baseline	7.7	1.7	7.7	2.1
Placebo	8.3	1.6	7.7	1.9
0.3mg/kg dose	8.0	1.9	8.4	1.3
0.6 mg/kg dose	7.7	1.8	8.4	1.4
1.0 mg/kg dose	8.2	1.9	8.6	1.4
Opitmal sustained dose (6 weeks)	8.3	1.9	9.0	1.0
Placebo in week 7	—	—	—	—
Reinstatement in week 8	9.0	1.1	9.1	0.9

For the six weeks of treatment, only those subjects have been selected who respond with at least a 25 percent improvement in the original trials on a paired-associate learning task. This task is used for selection since it is a generally more reliable measure of drug response (Swanson et al, 1991). Note that only fifty-five subjects have been used in the original reading trials, and forty-two of these have been judged to be responders. This response rate is not unusual in that about two-thirds to three-quarters of all ADHD subjects tend to respond to methylphenidate. Those who respond have then been maintained on their optimal dose, as determined in the original trials, for a six-week period then retested on equivalent forms of the same oral reading and reading comprehension measures. They have then been placed on placebo in the seventh week and reinstated on the same dose of methylphenidate in the eighth week. This has been done to see if their performance would decrease, as one might expect, in week seven without treatment but then improve again after treatment is resumed.

This is what appears to happen in the mixed group, as indicated in Table 2. They seem to improve their performance slightly over six weeks of treatment, drop off somewhat in week seven, and resume improvement in week eight. This finding only approaches statistical significance at the .08 level; but is statistically significant in a subgroup of those mixed subjects who had also demonstrated an improvement in their oral reading in the original trials. The pure group, on the other hand, seems to do about as well under placebo as they do on methylphenidate. There seems to be no dose effect for these findings, although there is a tendency for optimal treatment doses in the mixed group to occur more at the low or medium rather than at the high doses. Presence or absence of LD does not appear to affect results, although there are really too few subjects with LD to study this phenomenon effectively.

Conclusions

Further analyses of these results are still being conducted across other measures of drug response, including cognitive measures and teacher and parent ratings (Swanson et al, in press). What is of interest thus far in the findings just presented is that ADHD boys with conduct disorders seem to be somewhat more academically impaired than boys with only ADHD, although cognitive level appears the same for both groups. This would argue somewhat for possible inclusion of this group of ADHD boys in the SED category, in that they demonstrate a behavioral disorder as well as impaired education performance. Subjects who have only ADHD and no other disorders do not seem to demonstrate an impairment in academic functioning, at least as tapped by this extensive battery of tests. Only a handful of subjects in either group would seem to be in a position to qualify for the LD category. It should be noted that findings on psychoeducational testing and special education placement of children diagnosed with depression (Forness, 1988) and conduct disorders (Forness, Kavale & Lopez, in press) are similar. These studies also suggest that it is frequently only the child with two or more of these three disorders (i.e. ADHD, depression,or conduct disorders), plus a learning disability, who qualifies for special education services under the restrictive criteria used by some states, especially for the SED category.

The findings on whether methylphenidate (Ritalin) enhances reading performance are thus far very modest indeed. It appears that this may only be true for a very small subgroup of ADHD subjects. When a number of variables regarding diagnosis and measurement are rigorously controlled, only ADHD subjects who also have conduct disorders respond, and they respond only on reading comprehension. Furthermore, they can only be counted on to do so if they also respond on two other different measures of drug response. The relationship of these findings, to results of methylphenidate on other cognitive or behavioral measures await further analysis.

Special education teachers often do not receive much in the way of training on psychopharmacologic treatment, even though such treatment may be widely used in ADHD or other specific disorders (Forness & Kavale, 1988). They also seem not to receive much training on specific disorders. Such training may often not be very useful when it comes to choosing specific approaches to classroom instruction or management, as suggested by psychoeducational test results on this sample. There is indeed a formidable range of IQ and achievement levels within this single diagnostic category. The sample also seems to range across at least two special education categories and probably well into the non-eligible range of children who could indeed find themselves in regular classrooms without benefit, and possibly without need, of any special education services whatsoever. ⬆

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